



Florida State Cancer Plan 2010 Guide

FLORIDA DEPARTMENT OF
HEALTH

Building Blocks
to Reduce the Burden
& Enhance Cancer Collaboratives



Charlie Crist
Governor

Ana M. Viamonte Ros, M.D., M.P.H.
State Surgeon General

September 2010

Dear Colleague:

Cancer prevention, education, and screening are crucial for Florida since the state ranks second in the nation in cancer incidence, with approximately 100,000 new cancers diagnosed each year, and second in mortality with 40,000 deaths from this disease. While we have made significant strides in lessening the morbidity and mortality of this disease each year, much more still needs to be done. To that end, we have developed the 2010 Florida Cancer Plan and the accompanying Florida Cancer Plan Guide.

The Department encourages interested stakeholders to review and utilize the 2010 Florida Cancer Plan and the accompanying Florida Cancer Plan Guide in their cancer control efforts. Both the Plan and the Guide were produced through a collaborative effort from many of Florida's dedicated organizations and individuals. These partners graciously committed their time and expertise to create this comprehensive blueprint and resource for planning, implementing, and documenting an organized and collaborative approach to success.

I would like to thank all of Florida's partners for their leadership in creating these helpful tools, their compassion in helping cancer survivors and loved ones, their countless volunteer hours, and their relentless dedication in overcoming the challenges inherent in cancer. I am confident that this Plan and Guide will assist you to maximize resources in reducing the burden of cancer.

Sincerely,

A handwritten signature in blue ink that reads "Ana Maria Viamonte Ros".

Ana M. Viamonte Ros, M.D., M.P.H.
State Surgeon General

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PURPOSE

The Florida Comprehensive Cancer Control Program on behalf of the state councils and regional collaboratives is pleased to present the ***Florida State Cancer Plan 2010 Guide: Building Blocks to Reduce the Burden and Enhance Cancer Collaboratives***. This Guide provides tools and resources to assist cancer stakeholders in implementing cancer control efforts and was designed to be used in coordination with the ***Florida State Cancer Plan 2010*** (to view in its entirety, please visit <http://www.doh.state.fl.us/family/cancer>).

The *Florida State Cancer Plan 2010* provides cancer incidence, mortality, and site-specific data, and outlines the state's goals and strategies to reduce the cancer burden on Floridians. It also provides a historical perspective on the state's cancer control efforts. The Guide instructs future cancer efforts by mapping out a process for determining action steps, aligning resources, and measuring impact through the instruction of practical information and sample tools. Finally, the Guide contains instructions on how to complete an Action Plan (see page 31). Regional cancer collaboratives are strongly encouraged to map out their action steps, align resources, and measure their impact.

This Guide is an abbreviated version of the Centers for Disease Control and Prevention's (CDC) Building Blocks framework. It is an introductory approach to formalizing a structure and unified process for Florida's cancer collaboratives. For a more comprehensive and broader breadth of detail, please view the CDC's website for the *Guidance for Comprehensive Cancer Control Planning Toolkit* in its entirety.

ACKNOWLEDGEMENTS

Thank you to all of the extremely knowledgeable cancer partners whose tools and resources we learned, adapted and incorporated into this guide. Also, thank you to the many Floridians whose commitment, contributions, and participation in cancer control activities have strengthened the fight against cancer.

Section 1: Background

NATIONAL PERSPECTIVE



CENTERS FOR DISEASE CONTROL AND PREVENTION (CDC)

The CDC defines comprehensive cancer control as “an integrated and coordinated approach to reducing cancer incidence, morbidity, and mortality through prevention (primary prevention), early detection (secondary prevention), treatment, rehabilitation, and palliation.”

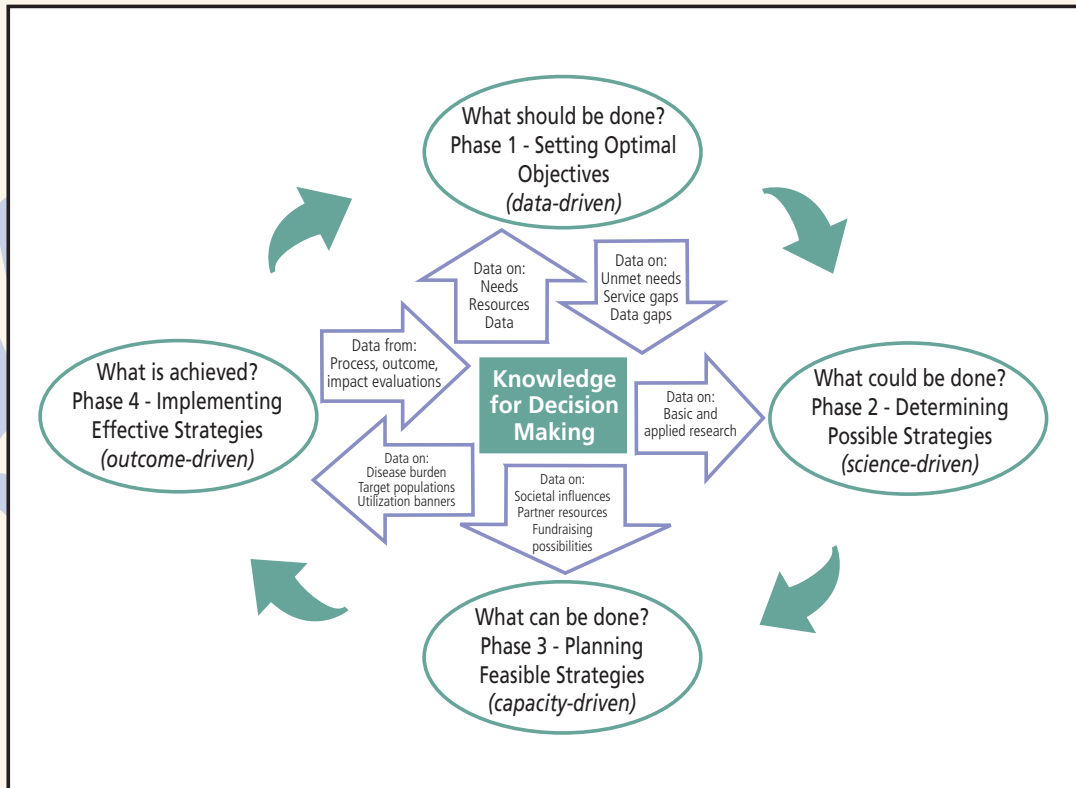
In 1998, the CDC established the National Comprehensive Cancer Control Program (NCCCP) to provide guidance to states, territories and tribes to form coalitions, assess the burden of cancer, determine priorities, and develop and implement cancer plans. Over the past twelve years, the NCCCP has grown from six to 69 funded states, territories, and tribal programs.



To learn more about the national program visit <http://www.cdc.gov/cancer/ncccp/about.htm>.

FRAMEWORK FOR COMPREHENSIVE CANCER CONTROL

The framework for comprehensive cancer control focuses on four key phases of planning. Phase 1 is setting the objectives based on data, Phase 2 is utilizing existing research to determine the strategies for meeting the objectives, Phase 3 is planning the strategies that are feasible to implement, and Phase 4 is implementing the strategies that are effective and yield desired outcomes.



Source: Adapted from Journal of Public Health Management Practice 2000;6(2):67-78

Florida Perspective



FLORIDA CANCER COUNCILS

The state of Florida has had a cancer plan for almost 30 years. The first Florida Cancer Plan was written and approved by the Governor-appointed Florida Cancer Control and Research Advisory Council (CCRAB) in 1981. At the 2004 national Comprehensive Cancer Control Leadership Institute, a secondary statewide body was formed, the Florida Cancer Plan Council (FCPC) under the guidance of the CDC. Through the dedication of CCRAB and FCPC members, the current *Florida State Cancer Plan 2010* was created. A broader description of the *Florida State Cancer Plan 2010* is provided on (page 10) of this Guide. To view the *Florida State Cancer Plan 2010* please visit: <http://www.doh.state.fl.us/family/cancer>.

FLORIDA COMPREHENSIVE CANCER CONTROL INITIATIVE

Cancer control efforts are guided by the leadership of CCRAB and FCPC and are implemented at the local level through a network of volunteer groups called collaboratives. In 2000, the University of Miami, Sylvester Comprehensive Cancer Center received funding from the CDC to establish the Florida Comprehensive Cancer Control Initiative (FCCCI). The FCCCI launched four locally organized partnerships called regional cancer control collaboratives which covered all 67 Florida counties.

FLORIDA COMPREHENSIVE CANCER CONTROL PROGRAM

In 2001, the CDC redirected their cancer control efforts and began awarding funds through cooperative agreement (U55/CCCU421918) with state health departments, including the Florida Department of Health. This funding permitted the creation of the Comprehensive Cancer Control (CCC) Program. The CCC Program worked in cooperation with the FCCCI to continue the support for the regional cancer control collaborative network.

FLORIDA REGIONAL CANCER COLLABORATIVES

Over the years, the CCC Program has provided financial support to the regional cancer collaboratives through a competitive process. Interested collaboratives are required to address one or more of the prioritized goals and strategies outlined in the *Florida State Cancer Plan 2010* and complete the Action Plan (see page 31).

Since the inception of the regional cancer collaboratives, there has been much success in providing education, promoting healthy messages to increase cancer prevention, creating stronger partnerships, producing better linkage for services and enhanced communication among cancer stakeholders.

TAKE ACTION!

GET INVOLVED IN FLORIDA'S COMPREHENSIVE CANCER CONTROL ACTIVITIES

For more information on the CDC funded Comprehensive Cancer Control Program, the *Florida State Cancer Plan 2010*, or the regional cancer collaboratives please visit:

Comprehensive Cancer Control Program – www.doh.state.fl.us/family/cancer.

To contact a Comprehensive Cancer Control Program staff member please e-mail: cancer@doh.state.fl.us.

FLORIDA REGIONAL CANCER CONTROL COLLABORATIVES

For more information about a specific regional collaborative please visit:

Northwest FL Collaborative website at <http://www.nwfcc.net/>. The collaborative includes individuals from Bay, Calhoun, Escambia, Franklin, Gadsden, Gulf, Holmes, Jackson, Jefferson, Leon, Liberty, Madison, Okaloosa, Santa Rosa, Taylor, Wakulla, Walton, Washington counties.

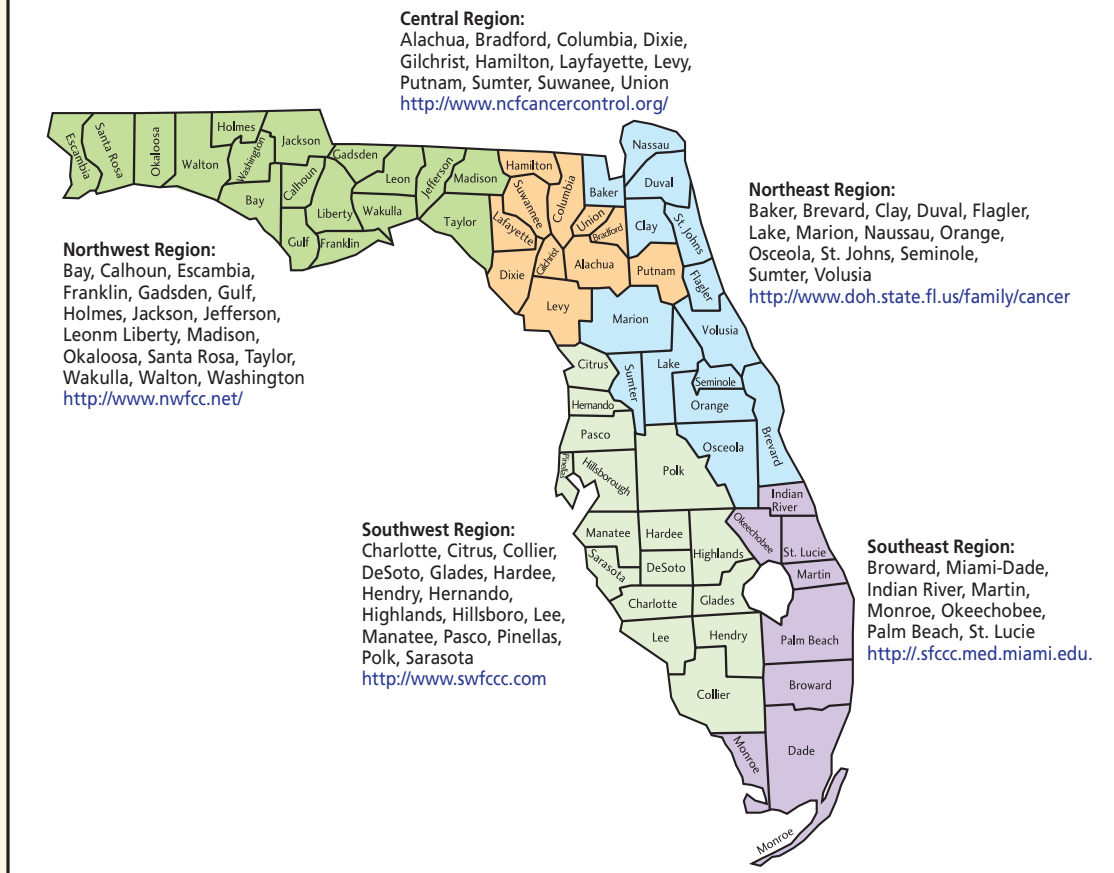
North Central FL Collaborative website at <http://www.ncfcancercontrol.org/>. The collaborative includes individuals from Alachua, Bradford, Columbia, Dixie, Gilchrist, Hamilton, Lafayette, Levy, Putnam, Sumter, Suwannee, Union counties.

Southeast FL Collaborative website at <http://sfccc.med.miami.edu/>. The collaborative includes individuals from Broward, Miami-Dade, Indian River, Martin, Monroe, Okeechobee, Palm Beach, St. Lucie counties.

Southwest Collaborative website at <http://swflccc.com>. The collaborative includes individuals from Charlotte, Citrus, Collier, DeSoto, Glades, Hardee, Hendry, Hernando, Highlands, Hillsborough, Lee, Manatee, Pasco, Pinellas, Polk, Sarasota counties.

Northeast Collaborative website is not yet developed. The collaborative includes individuals from Baker, Brevard, Clay, Duval, Flagler, Lake, Marion, Nassau, Orange, Osceola, St. Johns, Seminole, Sumter and Volusia counties.

Regional Cancer Control Collaboratives



Section 2: Florida Cancer Plan

This *Florida State Cancer Plan 2010* was developed based on the tenets of the previous *Florida Cancer Plan 2006*. Analysis of the previous plan's cancer plan goals resulted in redefining and simplifying them into four prioritized goals. The *Florida State Cancer Plan 2010* was designed to provide a blueprint and a list of options for cancer stakeholders to establish a course of action in preventing, reducing, and controlling cancer.

GOALS AND OVERARCHING STRATEGIES

The *Florida State Cancer Plan 2010* provides health information and data on nine cancer sites and classifications include breast, cervical, childhood, colorectal, lung and bronchus, melanoma of the skin, oral, ovarian, and prostate.

The contributing authors of the plan also identified ten overarching strategies, which are applicable to each of the nine cancer site classifications, and are fundamental when conducting cancer control efforts for Floridians. These strategies are infrastructure, lifestyle, disparities, access to care, education, research, survivorship, policy legislation, environmental factors, and patient navigation.

The *Florida State Cancer Plan 2010* provides an overview of the cancer burden in Florida from the state's cancer registry, the Florida Cancer Data System, and the findings from the most recent nationally sponsored Behavioral Risk Factor Surveillance System report on the state's screening practices (see page 20 of this guide for more information). Additionally, the plan outlines health disparities by population, specific behavioral and preventive measures that may reduce one's risk of cancer, and early detection techniques. Each of the data points are depicted for nine specific cancer sites or classifications.

For more specific information, please refer to page 15 in the *Florida State Cancer Plan 2010*.



FLORIDA CANCER PLAN GOALS

Goal 1: A coordinated approach among public and private cancer control stakeholders to implement cancer activities statewide

Goal 2: Floridians practice the healthy behaviors associated with prevention of cancer or to reduce risk

Goal 3: Floridians have access to appropriate health information and effective health services for the timely detection, diagnosis, and treatment of cancer

Goal 4: Floridians affected by cancer are aware of and have access to quality, appropriate services for quality of life, palliative care, and survivorship

OVERARCHING STRATEGIES

Category

- Infrastructure
- Lifestyle
- Disparities
- Access to Care
- Education
- Research
- Survivorship
- Policy Legislation
- Environmental Factors
- Patient Navigation

CANCER SITES

Category

- Breast
- Cervical
- Childhood
- Colorectal
- Lung and Bronchus
- Melanoma
- Oral and Pharyngeal
- Ovarian
- Prostate

The document entitled *Florida State Cancer Plan 2010* provides an expanded description of the goals and strategies. To view in its entirety, please visit <http://www.doh.state.fl.us/family/cancer>. A review of the plan is critical to the effective use of this guide. This guide provides tools and resources to assist cancer stakeholders in implementing cancer control efforts and was designed to be used in coordination with the *Florida State Cancer Plan 2010*.

Collaborative members should use the guide to map out the action steps, align resources, and measure the impact of the goals and strategies described in the plan.



Section 3: Framework For Cancer Control Efforts

There are a multitude of cancer control models and frameworks to assist and support cancer efforts. The Florida CCC Program has selected to adopt the CDC's Guidance for Comprehensive Cancer Control Planning, Volume 1 and 2. To view the guidance information and assistive toolkit please visit

<http://www.cdc.gov/cancer/ncccp/pdf/Guidance-Guidelines.pdf> for Volume 1, and

<http://www.cdc.gov/cancer/ncccp/pdf/Guidance-Toolkit.pdf> for Volume 2.

In 2002, the NCCCP and national partners developed the *Comprehensive Cancer Control Planning Guidance and Toolkit* to provide a framework for states, territories, and tribes on how to review their existing cancer data, develop a plan for addressing cancer and identify priorities for their specific jurisdiction.

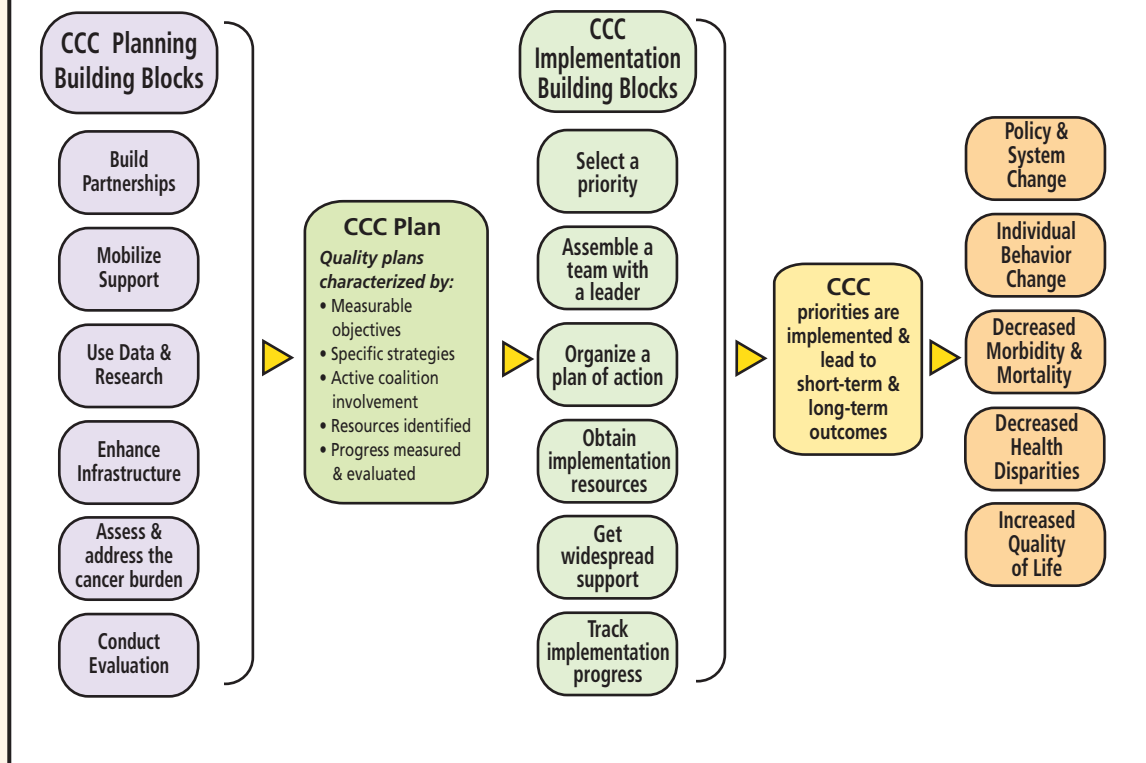
Currently, the CDC is working with a contractor to design a CCC Toolkit for Implementation to be disseminated 2011. However, for inclusion in this Guide, the Florida CCC Program was provided a portion of the content from the CDC Toolkit for Implementation including the six key elements for implementation referred to as the "building blocks."

The *Florida State Cancer Plan 2011 Guide* uses these "building blocks" to provide structure and guidance for regional cancer collaboratives in coordinating and mapping their cancer control activities. The guide also provides sample tools and resources.

Once a regional collaborative has identified the prioritized goal and strategy, they will navigate through the building blocks to direct their efforts and utilize the Action Plan (see page 31) to outline, monitor, and evaluate work.



Conceptual Framework for Comprehensive Cancer Control Planning Building Blocks



Presented by Strategic Health Concepts at the Comprehensive Cancer Control Leadership Institute (CCCLI). June 7-10, 2010 - Los Angeles, CA.

BUILDING PARTNERSHIP

Every successful local implementation of the state cancer plan begins with building a strong partnership. A collaborative must build partnerships to increase awareness and involvement of interested individuals and organizations from different disciplines and sectors including providers, public and private healthcare facilities, non-profit organizations, insurance companies, businesses, cancer survivors, government, colleges, and universities. Successful collaboratives require a strong, integrated group of individuals. Large, inclusive, and diverse memberships produce effective networks. The quantity and quality of members ensures that responsibilities can be shared and delegated to the appropriate stakeholders to ensure achievement of the goals.

Each collaborative must identify and develop their own leadership and workgroup structure. The leadership can provide the foundation for recruiting new partners, assessing the collaborative's needs and facilitation of the Action Plan. A workgroup structure should be organized based on the goals in the Action Plan.

Communication is vital in the development and sustainability of a partnership. Sharing information through face-to-face meetings, conference calls, and/or electronic communications are ways to recruit and connect partners. Each collaborative should establish a means to engage and inform their partners. The CCC Program employs several avenues to communicate with partners including disseminating a monthly, e-newsletter to engage and routinely inform statewide cancer stakeholders on current cancer control efforts. Each e-newsletter includes the following sections: Department of Health Spotlight, Survivors' Corner, Tools and Resources, Cancer Events, Grant Opportunities, and Cancer News Articles.

Take action!

1. Identify which individual(s) or agency(ies) will help the collaborative to achieve its objectives and strategies, and recruit them to participate.
2. Ensure collaborative participants have experience working in the target communities and come from diverse backgrounds.
3. Assess the membership from initiation and throughout the life cycle of the partnership. A checklist (see page 15) will help a collaborative outline its inter-organizational partners that should be or are involved.
4. Decide the method of communication that will be used to involve and inform potential partners. This information will help in the completion of column six (Person Responsible) and seven (Communications Plan) of the Action Plan (see page 31).
5. To join the Cancer Stakeholder e-mail distribution list, send an email to Cancer@doh.state.fl.us.

Sample Collaborative Membership Checklist

Please rate the participation of the following organizations in the areas of their importance to the work of the collaborative, the feasibility of getting them involved, and if they already participate, the level of their involvement. A "1" indicates least and a "5" indicates most.

Government	Importance	Feasibility	Involvement
Elected Official (national, state, and local)	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
State and Local Health Department	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
Other _____	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
Education	Importance	Feasibility	Involvement
<i>Education (K-12)</i>			
School Superintendent(s)	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
School Staff	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
PTA Organizations	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
School Resource Officer	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
Education	Importance	Feasibility	Involvement
<i>Colleges & Universities (if they are present in the community)</i>			
Administration	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
Student Affairs	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
Fraternities and Sororities	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
Other _____	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
Health Care Community	Importance	Feasibility	Involvement
Hospitals/Trauma Centers	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
Physicians	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
Pediatricians	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
Medical Associations	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
Nurses	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
Other _____	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
Businesses/Employers	Importance	Feasibility	Involvement
Insurance Companies	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
Local Major Employers	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
Media	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
Television Stations	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
Radio Stations	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
Newspapers	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
Other _____	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
Youth & Youth Organizations	Importance	Feasibility	Involvement
SWAT Groups	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
Boys & Girls Clubs	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
Boy Scouts/Girl Scouts	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
Other _____	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
Community	Importance	Feasibility	Involvement
Parent Groups	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
Faith Community	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
Citizen Activist Groups	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
Civic Groups	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
Minority/Culturally Specific Organizations	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
Other _____	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5

SAMPLE INVITATION LETTER

Dear **[insert recipient's title and name]**:

I am writing you on behalf of the **[insert collaborative's name]**. You are invited to participate in the local cancer control efforts to build partnerships, share resources, and reduce the cancer burden for our community. The **[insert collaborative's name]** membership is comprised of volunteer, community individuals, like you, who are interested in enhancing cancer prevention, education and services for **[insert county or geographical area]**.

We believe that you are committed to improving community health and that you would be an ideal partner in this work. We know having participation from strong leaders in the community, like yourself, the **[insert collaborative's name]** will have a greater impact on reducing the burden of cancer in Florida.

We would like to invite two representatives from your organization who have an interest in advancing cancer prevention and control to attend an upcoming meeting. The meeting is scheduled for **[insert date and time]** at **[insert information about location]**. **[If you have conference call capability]**. The meeting will also be accessible via conference call by dialing **[insert conference call number and, if any, related codes]**.

I have enclosed a preliminary agenda. Please RSVP by **[insert information regarding postal mail, fax, or email]** by **[insert date]**. If you have any questions, please contact **[insert name]** by phone at **[insert phone number]** or by e-mail at **[insert email address]**.

We look forward to your insight and involvement with the comprehensive cancer control efforts.

Sincerely,

[Name of chair or designated lead]

[Title/position], [Organization, agency, or collaborative's name]

MOBILIZE SUPPORT

Mobilization is a dynamic, ongoing process to marshal partners' support for implementing the Action Plan. Mobilizing partner support is necessary for taking action, leveraging political will, advocating for additional funding and resources, and enhancing visibility and a broader base of support. By building an expansive collaborative base, you will establish a strong, unified force to enact local cancer control efforts. Initially, this may be essential since resources are limited.

Periodically, collaboratives must assess the value that each partner brings. This value is translated into resources and can be entered into the third column (Resources Required) of the Action Plan (see page 31). The CCC Interest Form is an example of how this information can be recorded and collected (see page 18). Over time, collaboratives may need to seek new partners in order to advance progress and embark in new initiatives.

The CDC toolkit states “the objective for mobilizing support is to improve the use of existing resources for cancer programming and to increase the level of support overall”. Community assessments and surveys (see page 19) can assist a collaborative in identifying available resources and determining the tools needed for success. Collecting this information during the planning phase can enhance success and lead to greater support over time. Look for creative ways of identifying and securing needed resources.

Support can be provided as in-kind through personnel, resources, or funding. Potential funding sources could include: Centers for Disease Control and Prevention (CDC), National Cancer Institute (NCI), state and county health departments, pharmaceutical company grants, university grants, foundation grants, and private funding to name a few. Two examples of websites that provide links to government agencies and private foundations (such as American Cancer Society and Susan G. Komen for the Cure) that support cancer research are:

Community of Science <http://fundingopps.cos.com/> and National Cancer Institute <http://www.cancer.gov/researchandfunding/organizations>.

Take action!

1. Periodically assess your partners and their role in the collaborative.
2. Conduct community assessments or surveys to identify existing resources.
3. Think creatively about enhancing support, including diverse fiscal opportunities, to accomplish the goals outlined in the Action Plan.

Comprehensive Cancer Control Interest Form

Directions: Please complete the form below if you are interested in, and available to, serve as a member of the **[insert name of collaborative]**. This form may also be used to provide us with information about other individuals that may be interested and available to serve.

Interested Member's Contact Information-

Name:

Title:

Organization:

Address:

Phone Number:

Fax:

E-mail:

- ☐ Yes, I am interested in participating in the **[insert name of collaborative]**.
- ☐ Yes, I am also interested in a leadership position.
- ☐ No, I am not interested in participating in the comprehensive cancer control development.

I recommend the following people/organizations to participate in **[insert name of collaborative]**.

Name:

E-mail address:

The resources that I can contribute to the collaborative are: *(please list any resources such as meeting space, personnel, website expertise...)*

Please return this survey via fax **[insert fax number]** or email **[insert email address]** by **[insert due date]**.

Sample Community Survey

Demographics

Sex/gender:

Male

Female

Age:

☐ 18 – 34

☐ 35 – 64

☐ 65+

Race/ethnicity:

(check all that apply)

☐ African American

☐ American Indian/Alaska Native

☐ Hispanic/Latino/a

☐ White/ Caucasian

Other (specify): _____

Have you ever been told that you have: (check all that apply)

☐ Cancer

☐ High Cholesterol

☐ Diabetes

☐ High Blood Pressure

☐ Asthma

☐ Arthritis

Other (specify): _____

If you answer “no” to any of the following questions, please circle the number of the THREE you would MOST like to see addressed in the community. (Please circle only three.)

1. Do MOST businesses or public buildings in the community have areas that prohibit smoking?

☐ Yes ☐ No ☐ Don't Know

2. Do you have access to public trainings on cancer screening?

☐ Yes ☐ No ☐ Don't Know

3. Do you have access to public trainings on cancer treatment?

☐ Yes ☐ No ☐ Don't Know

4. Do you have access to health care providers that specialize in cancer treatment in your community?

☐ Yes ☐ No ☐ Don't Know

5. Does your community have affordable, convenient public transportation?

☐ Yes ☐ No ☐ Don't Know

6. Do you have access to free cancer screenings?

☐ Yes ☐ No ☐ Don't Know

7. Do you have access to a nonprofit, like American Cancer Society, that provides cancer information and educational classes?

☐ Yes ☐ No ☐ Don't Know

8. Are you aware of a “navigator” or community health worker program in your community?

☐ Yes ☐ No ☐ Don't Know

9. Is there a policy that you think can help make cancer prevention and control better in your community?

☐ Yes ☐ No ☐ Don't Know

If yes, please describe:

Return this form to:

USE DATA AND RESEARCH

The selection of prioritized goals and strategies should be data driven. In the Action Plan, a collaborative must understand and analyze data to complete column one (Strategies) and column five (Targets and Measures). Data and research: 1) influence partners' perception of their role in cancer control, 2) create an interest to mobilize support, 3) explain the outcomes of previous strategies, and 4) provide a basis for program specific measurements. Data is available from a number of sources including, state, and federal websites. The following data sources are recommended for Florida cancer stakeholders.

Florida Cancer Data System

<http://fcds.med.miami.edu>

The Florida Cancer Data System (FCDS) is Florida's statewide, population-based cancer registry that began operation in 1980 as a pilot project. FCDS has been collecting cancer incidence data since 1981 and is administered by the Florida Department of Health and operated by the Sylvester Comprehensive Cancer Center at the University of Miami Miller School of Medicine.

Behavioral Risk Factor Surveillance System

http://www.doh.state.fl.us/disease_ctrl/epi/brfss/reports.htm

Florida is one of 50 states conducting the Behavioral Risk Factor Surveillance System (BRFSS) with financial and technical assistance from the CDC. This state-based telephone surveillance system is designed to collect data on individual risk behaviors and preventive health practices related to the leading causes of morbidity and mortality in the United States.

Health Information National Trends Survey

<http://hints.cancer.gov/>

The Health Information National Trends Survey (HINTS) was developed by the National Cancer Institute, Health Communication and Informatics Research Branch of the Division of Cancer Control and Population Sciences. HINTS was created to monitor changes in the rapidly evolving field of health communication. The survey data can be used to understand how adults use different communication channels to obtain health information for themselves and their loved ones, and to create more effective health communication strategies across populations.

NCI State Cancer Legislative Database Program

<http://www.sclld-nci.net/index.cfml>

The National Cancer Institute's (NCI) State Cancer Legislative Database (SCLD) serves as an important resource for research and analysis of cancer-related health policy. Since 1989, NCI has monitored cancer-related state legislation and maintained the SCLD Program.

Take action!

1. Research and compile a variety of data to establish a baseline and monitor progress.
2. Learn more about the Florida Cancer Data System (see page 21).
3. Visit the FCDS website at <http://fcds.med.miami.edu/inc/datarequest.shtml> for information about data release procedures and web practices. Complete the FCDS IDEA User Account Form Researcher Request to obtain data that will help strategize priority actions.

QUICK FACTS:

Single largest population-based cancer incidence registry in the nation

Annual caseload: ~ 160,000 cancer abstracts per year

Existing database: 3.8 million cancer records, 6 million discharge records, and 3.5 million mortality records

State burden: Approximately 100,000 new cancers diagnosed and 40,000 cancer deaths occur each year

The Department of Health, Bureau of Epidemiology has contracted with the University of Miami's Miller School of Medicine since 1979 for the day-to-day operations of the statewide cancer registry, the Florida Cancer Data System (FCDS).

The Florida Cancer Data System is Florida's legislatively mandated, population-based, cancer registry. Under Section 385.202 *Florida Statutes*, each hospital and outpatient facility licensed in Florida must report to the Department of Health each patient diagnosed and admitted for treatment of cancer. Information to be reported, in addition to routine personal and demographic data, includes diagnosis, stage of disease, medical history, laboratory data, tissue diagnosis, and method(s) of treatment.

The FCDS has been collecting statewide cancer incidence from hospitals since 1981 and from ambulatory surgical centers, radiation therapy centers, private physicians, and pathology laboratories since 1997.

Data collected and coded by the FCDS are in accordance with national standards as put forth by the North American Association of Central Cancer Registries (NAACCR), and the FCDS uses the International Classification of Diseases – Oncology, 3rd edition (ICD-O-3) to code primary site and morphology.

The FCDS data are utilized to: (1) to monitor the occurrence of cancer; (2) to focus cancer control activities and the development of health and screening programs in the state; (3) inform health professionals and educate citizens regarding specific cancer risks; and (4) to aid in research studies.

Aggregate, de-identified data for the 80 malignant cancers and four benign/borderline central nervous system tumors collected by the FCDS are available online at:

<http://www.fcds.med.miami.edu/inc/statistics.shtml>.

Example output from the FCDS Interactive Rates Query Module

Incidence Rates Results

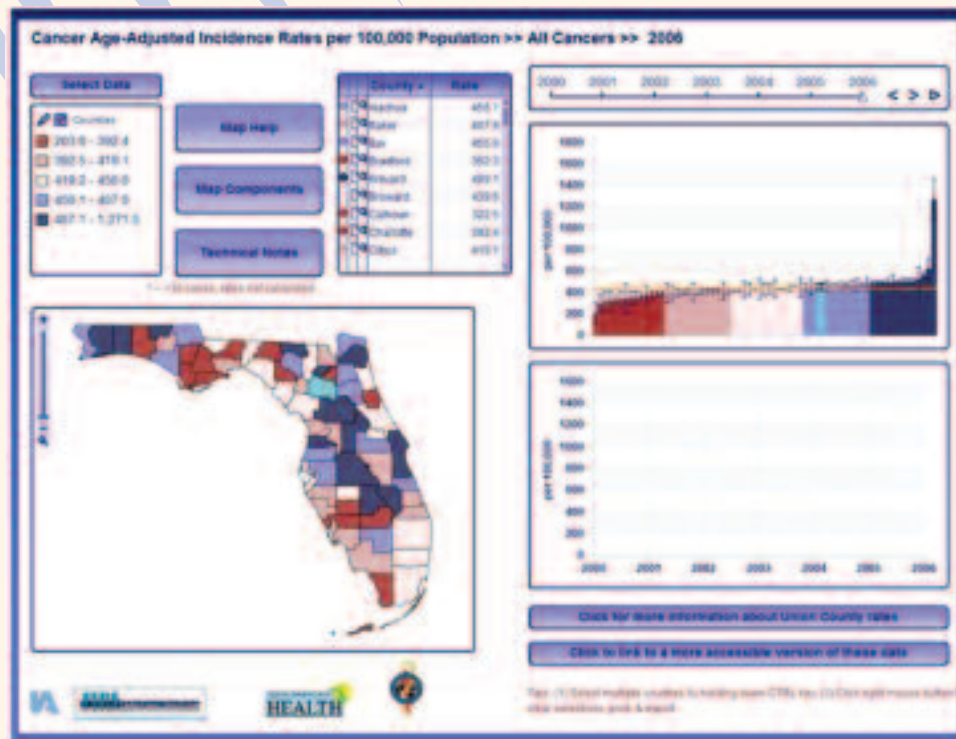
Site	County	DX Year	Sex	Race
Acute Lymphocytic Leukemia	ALACHUA	2006-Provisional	Male	White

	State			State	
	Rate	Rate		Rate	Rate
Age 0 to 4	.00	6.11	Age 45 to 49	.00	.73
Age 5 to 9	.00	4.17	Age 50 to 54	.00	.40
Age 10 to 14	.00	2.23	Age 55 to 59	.00	.21
Age 15 to 19	.00	1.32	Age 60 to 64	.00	1.50
Age 20 to 24	.00	.89	Age 65 to 69	.00	1.19
Age 25 to 29	.00	.69	Age 70 to 74	.00	1.97
Age 30 to 34	.00	.66	Age 75 to 79	.00	4.02
Age 35 to 39	.00	.20	Age 80 to 84	.00	1.95
Age 40 to 44	.00	1.27	Age 85 and Up	.00	1.95

Adjusted Rate	.00
State Adjusted Rate	1.68

Please select 'Interactive Rates and Maps' to access the data query system. Data can be queried by cancer site, diagnosis year, county, sex, race, and age. Age-adjusted rates are provided based on the data selection criteria. In addition, county-level cancer data can be viewed through an interactive mapping program, InstantAtlas, for all of Florida's 67 counties.

Example *InstantAtlas* Screen



A training module, entitled Data Access for Department of Health Personnel and Approved Researchers, providing step-by-step instruction is available at:
<http://www.fcds.med.miami.edu/inc/training.shtml#webmod>.

ENHANCE INFRASTRUCTURE

A collaborative's infrastructure is the framework for how the group is organized and how the work is conducted. Components of an infrastructure include human resources such as collaborative members as described in the Building Partnership section of this guide, as well as administrative processes. Both human resources and administrative processes must be developed and periodically evaluated to ensure that members' have a clear understanding of the collaborative's capacity and expectations for its operation.

During the formation stage, collaborative participants will determine the mission statement and objectives, and establish core functioning processes such as decision-making and communication. Through consensus, the collaborative will select the appropriate operational tools. These tools will serve as the manual for the collaborative by recording how the group was established, how members are retained, how leadership was chosen, and how decisions are made.

Ideal Documents	Example
Bylaws	Northwest Florida Cancer Control Collaborative Bylaws (visit other collaborative websites for additional examples) http://nwfcc.net/uploads/nwfccc_bylaws_1202010.pdf
Meeting Rules	Robert's Rules of Order Summary http://www.mass.gov/agr/agcom/docs/handbook/PDF/E%20-%20Robert's%20Rules%20of%20Order%20Summary.pdf
Collaborative Assessment Tool	Nutrition and Physical Activity Online Coalition Self-Assessment Tool (assesses infrastructure needs and capacity) https://doa.wi.gov/DHSSurveys/TakeSurvey.aspx?SurveyID=l4LJ373K
Position descriptions	National Network for Health, Tobacco-free Youth, Coalition Volunteer Job Description http://wch.uhs.wisc.edu/docs/PDF-Pubs/job_descriptions.pdf
Action plan	Florida Cancer Plan http://www.doh.state.fl.us/family/cancer/plan/plan20032006.pdf

The aforementioned list of documents is not exhaustive. To achieve statewide success in the reduction of cancer burden, each collaborative is encouraged to use the *Florida State Cancer Plan 2010* as the foundation for cancer control planning and implementation activities. The Florida Cancer Plan Council Member Profile Form (see page 24) identifies each member's interest and contribution to the infrastructure needed to achieve the Action Plan goals and objectives.

Take action!

1. Establish the collaborative's mission statement.
2. Identify a framework for collaborative's structure.
3. Review samples of existing tools and design the collaborative's guiding principles.
4. Routinely review and update the Action Plan to ensure coordination and support among partners.

Florida Cancer Plan Council

MEMBER PROFILE

This form is used to collect information regarding your interests and skills in order to better facilitate your involvement with the Florida Cancer Plan Council. This form will also identify your workgroup selection.

Submission of this form provides consent to capture this information in an electronic database for record keeping and communication purposes, to be maintained by the Florida Department of Health and the Florida Cancer Plan Council and will not be shared with outside entities.

MEMBER INFORMATION

Name: _____
Name and credentials Title

Name of the Alternate to the Florida Cancer Plan Council from your organization:

Name and credentials Title

Organization: _____

Mailing Address: _____

Phone: _____ Fax: _____ E-mail: _____

The four goals of the Florida Cancer Plan 2010 are:

Goal 1: A coordinated approach among public and private cancer control stakeholders to implement cancer activities statewide.

Goal 2: Floridians practice the healthy behaviors associated with prevention of cancer or to reduce risk.

Goal 3: Floridians have access to appropriate health information and effective health services for the timely detection, diagnosis, and treatment of cancer.

Goal 4: Floridians affected by cancer are aware of and have access to quality, appropriate services for quality of life, palliative care, and survivorship.

Which goal(s) are you interested in working on?

- ☐ Goal 1: A coordinated approach among public and private cancer control stakeholders to implement cancer activities statewide
- ☐ Goal 2: Floridians practice the healthy behaviors associated with prevention of cancer or to reduce risk
- ☐ Goal 3: Floridians have access to appropriate health information and effective health services for the timely detection, diagnosis, and treatment of cancer
- ☐ Goal 4: Floridians affected by cancer are aware of and have access to quality, appropriate services for quality of life, palliative care, and survivorship

Cancer Control Expertise / Interests (state below):

ASSESS AND ADDRESS CANCER BURDEN

The purpose of this section is to provide an overview of the key steps involved in compiling relevant data to summarize the cancer burden for your region. The *CDC Planning Guidance and Toolkit* states that assessing and addressing the cancer burden “remains the crux of a meaningful comprehensive cancer control program, however is augmented by the other building blocks.” Completing these steps will help to assure that the collaborative has the best information available to complete the Action Plan. To achieve long-term goals and population-level change, the completed Action Plan should parallel the state plan priority strategies as defined by the state councils on a yearly basis, whenever possible.

There are multiple data sources available to determine cancer morbidity and mortality as well as to assess individual risk behaviors and preventive health practices related to cancer. Sources for Florida specific data include the FCDS, the BRFSS, and the Florida Annual Morbidity Statistics Report. For additional information on data sources please see the Use Data and Research section on page 20 of this Guide.

Take action!

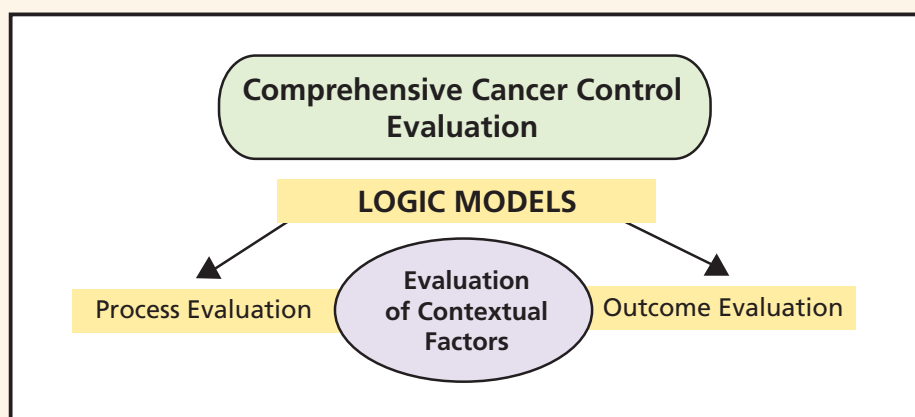
1. Provide relevant cancer data to collaborative participants.
2. Assess gaps and disparities in data.
3. Identify goals and action steps based on reliable data.
4. Create workgroups to address data needs.



CONDUCT EVALUATION

Evaluation is the systematic collection, analysis, and use of program information for monitoring, program improvement, outcome assessment, planning, and policy-making. More simply, evaluation is a process that helps a collaborative assess the strengths and weaknesses of their activities and identifies areas for improvement. Evaluation is most effective when it is viewed as an integral part of the entire planning process and initiated at the beginning of the project.

There are many ways to conduct evaluation but no one best way to do any evaluation. Good evaluation requires thinking through the questions that need to be answered (what information is needed), identifies the type of program being evaluated, and considers how the information will be used. Evaluation does not have to be expensive or complicated to be effective. Some evaluations can be done at little cost, and can even be completed by persons who are not professional evaluators. The information included in the following Action Plan will assist you in making some of the decisions for planning an evaluation.



Evaluation has two functional roles, namely formative and summative (Scriven, M. 1967). According to Scriven, "formative evaluation is conducted to provide program staff evaluative information useful in improving the program" and "summative evaluation is conducted and made public to provide program decision makers and potential consumers with judgments about that program's worth or merit in relation to important criteria."

	Formative Evaluation	Summative Evaluation
Purpose:	Program improvement	Program accountability
General Question:	<ul style="list-style-type: none">• Is this educational program being implemented as planned to achieve set goals?	<ul style="list-style-type: none">• Did this educational program contribute to the planned impact and compensate the resources utilized?
Specific Questions:	<ul style="list-style-type: none">• What are the strengths and weaknesses?• What is working and not working?• Why is it working or not working?• How should it be improved?	<ul style="list-style-type: none">• What are the program results?• Did intended audience benefit from the program?• Was the program cost effective?• Is it worth it to continue this program?

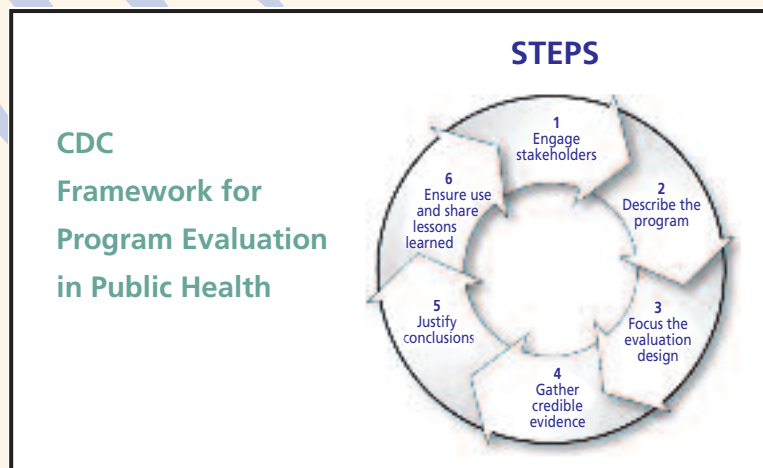
The CDC promotes the following steps in evaluation practice and standards, for effective evaluation:

STEPS IN EVALUATION PRACTICE

- **Engage stakeholders** - Those persons involved in or affected by the program and primary users of the evaluation
- **Describe the program** - Need, expected effects, activities, resources, stage, context, logic model
- **Focus the evaluation design** - Purpose, users, uses, questions, methods, agreements
- **Gather credible evidence** - Indicators, sources, quality, quantity, logistics
- **Justify conclusions** - Standards, analysis/synthesis, interpretation, judgment, recommendations
- **Ensure use and share lessons learned** - Design, preparation, feedback, follow-up, dissemination

STANDARDS FOR EFFECTIVE EVALUATION

- **Utility** - Serve the information needs of intended users
- **Feasibility** - Be realistic, prudent, diplomatic, and frugal
- **Propriety** - Behave legally, ethically, and with regard for the welfare of those involved and those affected
- **Accuracy** - Reveal and convey technically accurate information



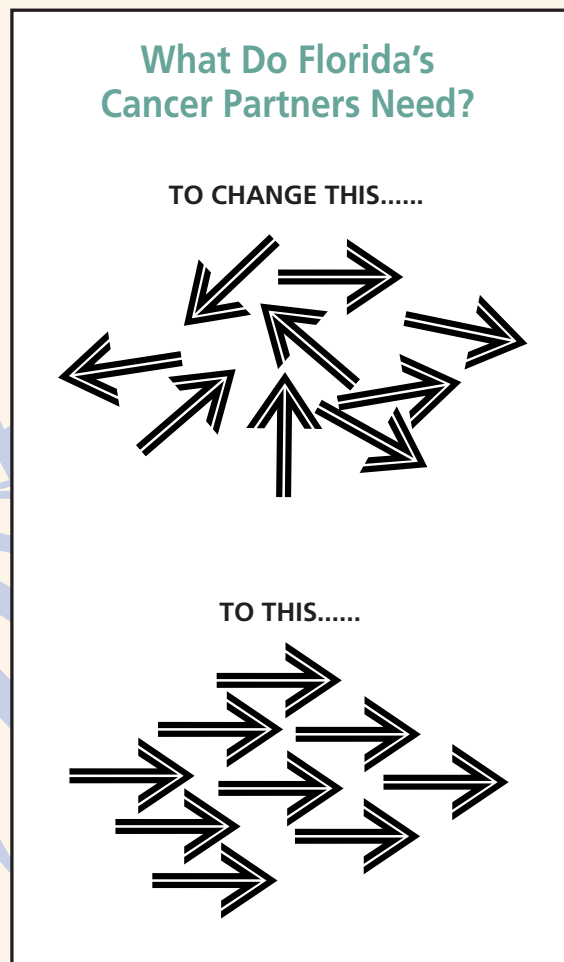
For a detailed description of each step and standard, review the Comprehensive Cancer Control Branch Program Evaluation Toolkit available at http://www.cdc.gov/cancer/ncccp/pdf/CCC_Program_Evaluation_Toolkit.pdf.

Sample Evaluation Questions

Evaluation Level	Evaluation Questions
CCC Initiative Process Evaluation	<p>EvaluationIs the comprehensive cancer control process working well?</p> <p>Are meetings regularly attended?</p> <p>Are members satisfied with the process?</p> <p>Are planning tasks being accomplished and are planning products being produced in a timely manner?</p>
CCC Initiative Outcome Evaluation	<p>Are the partnership’s overarching goals and objectives being achieved?</p> <p>Is infrastructure for cancer control being enhanced?</p> <p>Is support for the initiative being mobilized?</p> <p>Are data and research being utilized?</p> <p>Are partnerships being built?</p> <p>Is the cancer burden being assessed? Addressed?</p> <p>Is evaluation of planning process and outcomes being conducted?</p>
CCC Plan Process Evaluation	<p>Are strategies proposed in the plan being implemented?</p> <p>Are knowledge gaps being addressed through surveillance and research?</p> <p>Are the health systems issues impacting each cancer prevention and control intervention strategy being addressed?</p> <p>Are interventions being delivered—</p> <ul style="list-style-type: none"> • To subpopulations with high risk and high burden? • In a culturally appropriate manner? • In a timely manner? • In a cost effective manner? <p>Are implementation difficulties being successfully overcome?</p>
CCC Plan Outcome Evaluation	<p>Are the health outcomes anticipated by the partnership for each strategy being achieved?</p> <p>Has the baseline problem status identified by partners improved?</p> <p>Over time, has incidence, morbidity, and mortality from cancer decreased?</p> <p>Over time, are health disparities relating to cancer among subpopulations reduced?</p>

Centers for Disease Control and Prevention Guidance for Comprehensive Cancer Control Planning, Volume 1 retrieved from <http://www.cdc.gov/cancer/ncccp/pdf/Guidance-Guidelines.pdf>

Section 4: Florida Comprehensive Cancer Control Action Plan



There are many strong and successful cancer stakeholders throughout Florida. Each has developed customized plans for reducing the burden of cancer. While change in several areas is being achieved, the power of collective planning can maximize these efforts and lead to greater impact and increase sustainability in cancer control.

The CDC building blocks is a simple, strategic, and efficient approach. The building blocks are essential activities: build partnerships, mobilize support, use data and research, enhance infrastructure, assist and then address cancer burden, and conduct evaluation. Use the building blocks to move forward together with a clear vision of the most meaningful activities that can be conducted given the powerful and committed members present.

Each collaborative should review the six building blocks as a framework for coordinating and mapping their cancer control activities. Once a collaborative has identified the prioritized goal and strategy, the next step is to complete the Action Plan to systematically and logistically outline the cancer control efforts. Together, the *Florida State Cancer Plan 2010*, *Florida State Cancer Plan Guide 2010*, and the Action Plan serve as a basic toolkit that local areas can use to support statewide improvements in cancer prevention, early detection, treatment, and survivorship.

Action Plan - Template

Date: _____ Organization: *State name of individual or agency* _____

Goal: *State of Florida Cancer Plan Goal to be addressed* _____

Strategies	Action Steps	Resources Required	Timeframe	Targets and Measures	Person Responsible	Communications Plan
Identify the specific strategy	What will be done to accomplish this?	What resources are available? What resources are needed?	By when?	State what you are aiming to achieve – the intended outcome. State how progress will be determined- the means of measurement.	Name who or what agency will have lead?	Who is involved? What methods? What role? How often?
Column 1	Column 2	Column 3	Column 4	Column 5	Column 6	Column 7
1. Form groups of stakeholders to address strategies based on data, interest abilities, and resources in order to build momentum.	1. Send letters of invite to diverse stakeholders. 2. Establish meeting schedule	1. Designated coordinator. 2. Meeting space	1. Bi-weekly. 2. Bi-monthly	1. Have representation from five organizations by completion of year one.	1. Coordinator and collaborative chair.	1. Coordinator is responsible for disseminating on-going electronic correspondence. 2. Chair will provide oral and written partner updates at each meeting.

HOW TO COMPLETE THE ACTION PLAN

Step 1. *Choose a Goal*

Goals: Visionary statement of the end result or achievement in reducing the burden of cancer. Below are the *Florida State Cancer Plan 2010* goals.

FLORIDA CANCER PLAN GOALS

Goal 1: A coordinated approach among public and private cancer control stakeholders to implement cancer activities statewide.

Goal 2: Floridians practice the healthy behaviors associated with prevention of cancer or to reduce risk.

Goal 3: Floridians have access to appropriate health information and effective health services for the timely detection, diagnosis, and treatment of cancer.

Goal 4: Floridians affected by cancer are aware of and have access to quality, appropriate services for quality of life, palliative care, and survivorship.

Step 2. *Choose Strategy*

Strategies: defined steps needed to achieve a goal. These strategies are divided into two categories - overarching and by cancer site. Compared to objectives, strategies are general.

Step 3. Identify the Action Steps

Identify what action or work will be done to accomplish this strategy.

Step 4. Identify the Resources Required

Identify what resources are needed to address or achieve this strategy.

Identify what resources are available to address or achieve this strategy.

Step 5. State the Timeframe

State the chronological date as to when this action step will be completed.

Step 6. State the Targets and Measures

State what you are aiming to achieve, what the intended outcome is to be and how progress will be determined. State how progress will be to measured.

Step 7. State the Person Responsible

State who is the person(s) or what agency that will have lead on this action step.

Step 8. State the Communications Plan

State what other partners will be involved. State what their actions or role will be. And state the frequency, or how often they will be doing this action.

Section 5: Conclusion

The purpose of this *Florida State Cancer Plan 2010 Guide* is to assist Florida's cancer partners in the coordination and collaboration of cancer control efforts. This reflective approach to cancer control is a strategy to ensure that the state's cancer resources, from government programs to private and public organizations, are working together to reduce the burden of cancer in every community.

We hope this Guide will help new partners who are embarking upon the rewarding effort of building a local collaborative, as well as provide additional support to those established collaboratives that are evolving and thriving.

For more information about working with the CDC funded Comprehensive Cancer Control Program, the Florida Cancer Plan 2010, or the regional cancer collaboratives please visit www.doh.state.fl.us/family/cancer.



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